Secondary Uses of Clinical Data

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Introduction: NHII Roadmap

- "…a comprehensive set of Patient Medical Record Information (PMRI) standards can move the Nation closer to a healthcare environment where clinically specific data can be captured once at the point of care with derivatives of this data available for meeting the needs of payers, healthcare administrators, clinical research, and public health. This environment could significantly reduce the administrative and data capture burden on clinicians; dramatically shorten the time for clinical data to be available for public health emergencies and for traditional public health purposes; profoundly reduce the cost for communicating, duplicating, and processing healthcare information; and, last but not least, greatly improve the quality of care and safety for all patients."

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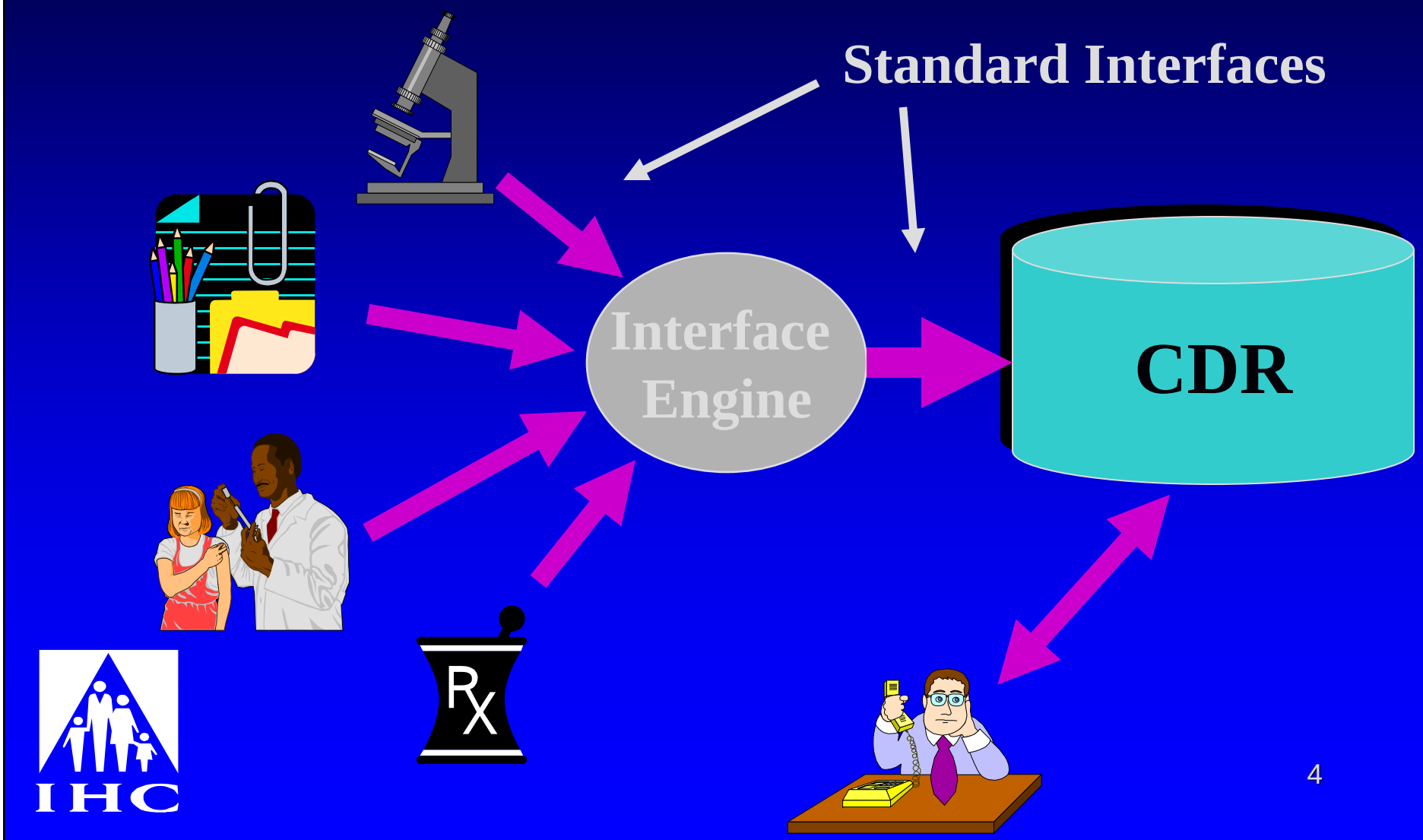
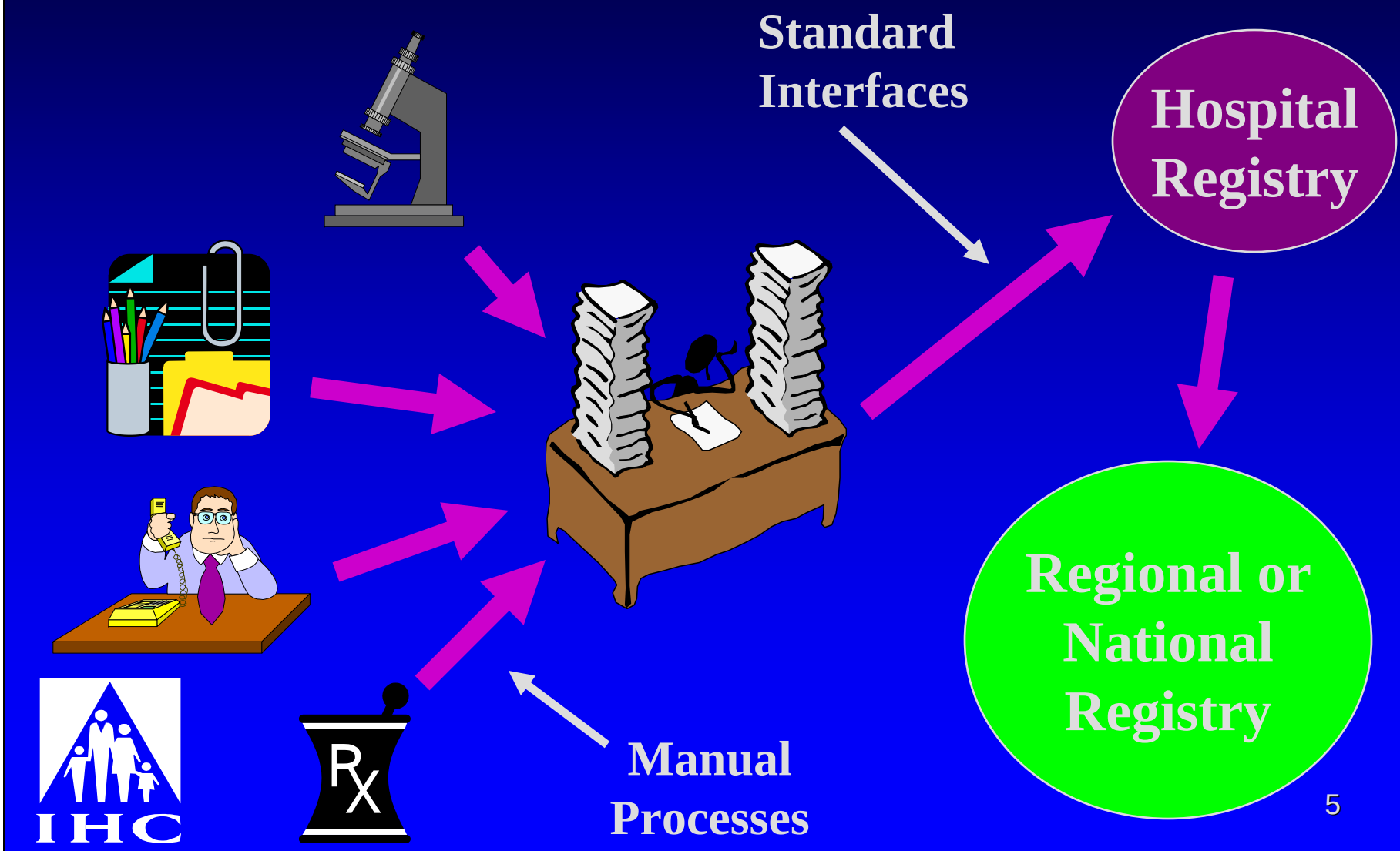
Definitions

- Primary use of data
  - Collection, processing, and display of data which is specific to an individual person for the purpose of providing care and services to that person
    - Includes data exchange with other sites for the care of the individual
- Secondary use of data
  - Processing and aggregation of data for uses other than direct patient care

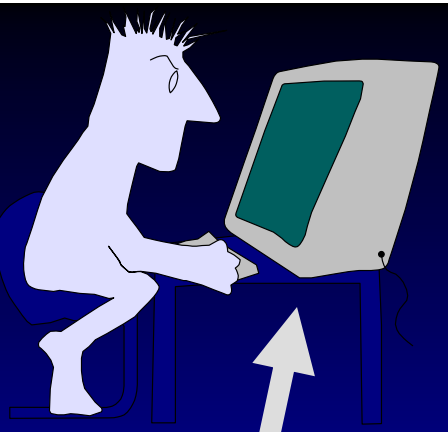
Typical IHC Clinical Data Flow (Primary use of data)

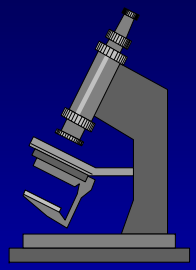


Cancer Registry Data Flow (Secondary use of data – manual)



Future?





Filtering
and Processing

Hospital
Registry

Interface
Engine

Standard
Interfaces

Regional or
National
Registry

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Secondary use of data at IHC

- Adverse drug event monitoring
  - Drug levels, antidotes, treatment of complications
- Nosocomial infection monitoring
  - Admission, fever, white count, chest x-rays
- Rule based billing
  - Labor and delivery
- Reportable diseases
  - Antigens, antibodies, cultures
- How am I doing reports
  - HgbA1c
- Clinical research
  - TURP, induction of labor prior to 39 weeks
  - Ventilator weaning

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Some possible secondary uses of data

- Billing
  - Direct assignment of billing codes from clinical data
  - Billing fraud detection
  - Billing justification – claims attachments
- Morbidity and mortality reporting
- Quality
  - HEDIS reports
  - Continuous quality improvement
- Patient safety reporting
  - Adverse event reporting
- Clinical trials
  - Post-marketing information on drugs and devices
  - Enrollment
- Clinical research
- Health population statistics
- Public health
  - Bio-surveillance
  - Reportable disease reporting
  - Disease and cancer registries

Why should NCVHS study this topic?

- What has already been done?
- Is it a feasible and cost effective approach?
  - What areas could offer greatest ROI?
  - Are any standards needed to enable secondary data use?
  - Are new policies needed?
  - Should we encourage demonstrations and pilots?
- Is this a topic that is appropriate for the quality workgroup?
- Is this a topic that is appropriate for the population statistics subcommittee?

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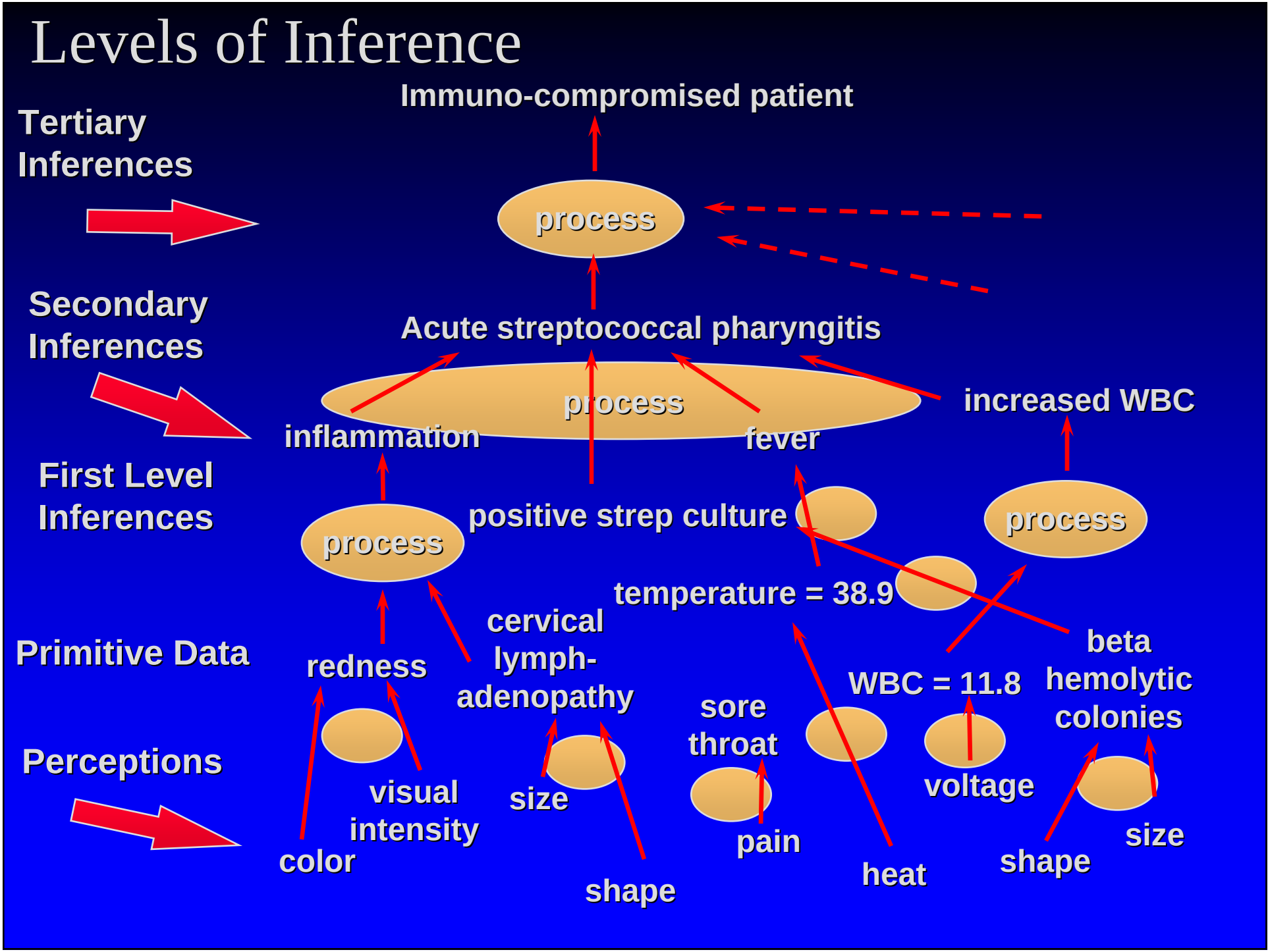
Levels of Inference



Observations on inference

- Data capture is costly in terms of people's time, computer programming, and instruments
- The closer you capture data to the level of perceptions and observations, the more inferences you can make
- Raw data allows testing whether the inference processes are accurate

Related issues

- The idea is that there could be a set of shared public computable rules or algorithms to assign classifications or to create inferences
  - Chris Chute – “Aggregation logics”
- It is often the case that there must be more than one secondary use of the data (clinical research, bio surveillance) to justify the cost of collecting the data

Not a data panacea

- You will still need other data collection instruments
- There are cases where you want to investigate issues where routine clinical data collection would not provide sufficient information
  - Population statistics
    - Diet, habits, exercise
  - Clinical trials
    - Specific research question

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